



December 2009

Re: A Decade of Little Progress Implementing Olmstead

In 1999 the U.S. Supreme Court, in *Olmstead v. Lois Curtis and Elaine Wilson*, stated loud and clear that it is a violation of the civil rights of Americans with disabilities to require a person to be institutionalized in order to receive necessary disability supports and services, if these services are more appropriately provided in the community. It is simply unacceptable, that 10 years later, there has been almost no progress reducing the numbers of Americans with disabilities, nationwide, who live in institutions. This report, “*A Decade of Little Progress Implementing Olmstead: Evaluating Federal Agency Impact After 10 Years*,” evaluates the efforts of key federal agencies to enforce the *Olmstead* decision over the past decade. We found next to no federal oversight of enforcement efforts and no repercussions for states who fail to make reasonable efforts to end unnecessary institutionalization. This approach is an affront to the people with disabilities. NDRN calls for more urgent federal enforcement of the *Olmstead* mandate.

With every year that passed in the last Administration, it appeared that federal efforts to spur *Olmstead* enforcement waned. This report highlights problematic trends like this and recommends a more effective, aggressive federal approach to bring about community integration. The research for the report was largely completed in September 2009. Since that time new leadership has been appointed to the U.S. Department of Justice (DOJ) and we’ve seen a renewed focus on *Olmstead* enforcement. Some welcome signs include:

- DOJ has been more proactive to reach out to members of the disability community to identify potential *Olmstead* cases where their participation might advance the law and help to clarify questions that remain unsettled after the Supreme Court’s decision. Questions which, if resolved, may remove barriers to individuals transitioning to the community.
- Recent DOJ investigations and filings under the Civil Rights of Institutionalized Persons Act (CRIPA) have made clear that *Olmstead* issues are deeply intertwined with problems of inadequate conditions, and solving these problems must look at whether the people in the facility belong there and whether the institution is complying with laws governing discharge planning and transition.

Hopefully, we will see a similar sense of urgency at the new HHS, Office of Civil Rights; and this aggressive commitment to enforcement of the Olmstead mandate will continue throughout the full Obama Administration and beyond. The ebbs and flows of budgets may pressure DOJ and the U.S. Department of Health and Human Services (HHS) to slow their commitment. However, America can't afford to slow down community integration. We have a generation of baby boomers facing disabilities as a result of aging, and thousands of recently wounded Iraq and Afghanistan veterans who deserve a future outside of institutions.

Sincerely,

Curtis L. Decker
Executive Director



**A Decade of “Little
Progress” Implementing
Olmstead:
Evaluating Federal
Agency Impact After 10
Years**

September 30, 2009

NDRN is the nonprofit

membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States. NDRN provides legally based assistance to P&As and works at the national and state levels to create a society in which people with disabilities are afforded equality of opportunity.

NDRN calls for more urgent federal action to compel compliance with the civil right to live in, work and enjoy the community.

EXECUTIVE SUMMARY

A decade ago, the U.S. Supreme Court ordered States to stop unnecessarily segregating individuals with disabilities in institutions in order to receive long term services.¹ Yet, ten years later, there has been little national progress moving people with disabilities out of nursing facilities and public institutions and into communities with supports.² People who want to live with their families and neighbors are still needlessly confined in large public and private institutions. NDRN calls for more urgent federal action to compel compliance with this civil right.

The National Disability Rights Network (NDRN) reviewed the efforts of the U.S. Department of Justice (DOJ) and the U.S. Department of Health and Human Services (HHS) -- two agencies charged with enforcing the Supreme Court's mandate. At HHS, we found a reliance on short-term voluntary financial incentives to encourage state compliance, coupled with a lack of monitoring and data collection about the effectiveness of these efforts. At DOJ, we found a lack of attention to enforcement of the ADA's integration mandate and many missed opportunities. Particularly when compared to DOJ's heavy focus on the need to fix up those crumbling old institutions that have a history of failing to keep its residents safe from abuse and neglect, this approach is an affront to people waiting -- often for decades -- in inappropriate institutions for the opportunity to return to the home communities.

The Obama Administration has announced that 2009 will be the "Year of Community Living."³ This is a hopeful sign of a renewed federal commitment to ending unnecessary institutionalization. There is no more time to waste. Our society is aging and more people are in need of community supports to remain employed and at home. Neither must we fail the hundreds of recent veterans who may return home to face institutionalization because of an inadequate community supports.

This report offers stories of individuals who are unnecessarily institutionalized and recommends practical strategies for HHS and DOJ to do more to spur compliance with

1 See *Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581(1999) holding that it is a violation of the Americans with Disabilities Act (ADA) to unnecessarily segregate an individual in an institution to receive care when these supports could be provided in the community.

2 See Braddock *et al.*, State of the States in Developmental Disabilities, University of Colorado 2008 at 101-305. (Some states have made significant progress moving individuals into appropriate community settings. However, a handful of states have actually increased their institutional populations.)

3 http://www.ich.gov/readmore/THE_YEAR_OF_COMMUNITY_LIVING.htm

Americans' civil right to remain living and working in the community. Americans waiting to leave institutions include both adults and children. For example:

Dan Smith (not his real name) is in his thirties and has Down Syndrome resulting in a mild intellectual disability. He successfully lived with his family in the community until 15 years ago when both his parents passed away, then he was moved into a 96-bed institution. He is capable of taking care of his needs, and can read, knows how to balance a checkbook, and held a job at a video store until the store closed. He is known as friendly with an engaging sense of humor. Mr. Smith would very much like to move to a small community-based group home in a setting closer to one of his siblings. He is frustrated after living so many years in an institution with very little privacy and severe limits on his choices, including those as basic as when to get up in the morning or when to turn out his reading light at night. His doctors at the institution have determined that the community would be more appropriate for Mr. Smith, but he remains needlessly confined in the institution.

David (not his real name) is 8 years old and has intensive mental health needs. He is eligible for Medicaid and his mother has asked for the therapeutic home-based mental health services that his doctor has prescribed. Medicaid has denied these medically necessary home based services and as a result, on numerous occasions, David has been forced to leave his family and go to the state hospital in order to obtain limited, episodic mental health treatment. At his young age removal from his family adds to the trauma he already experiences from his psychiatric impairment. David is at a critical period of development in his life. Denial of the services he needs like case management, crisis intervention, and in-home supports is causing long-term damage that can affect his later ability to live successfully in the community.



**A Decade of “Little Progress” Implementing
Olmstead:
Evaluating Federal Agency Impact**

The *Olmstead* Decision: A Mandate for Community Integration

A decade ago, In *Olmstead v. Lois Curtis and Elaine Wilson* the U.S. Supreme Court ruled that unjustified institutional isolation of people with disabilities is a form of discrimination under the Americans with Disabilities Act.⁴ To remedy or avoid such discrimination, States are required to provide community-based services for persons with disabilities, who are otherwise entitled to institutional services, when:

- 1) the State’s treatment professionals reasonably determine that community placement is appropriate;
- 2) the person does not oppose such placement; and,
- 3) the placement can reasonably be accommodated, taking into account resources available to the State and the needs of others receiving state-supported disability services.⁵

The ADA’s reasonable accommodation regulation does not require states to make “fundamental alterations” in its services or programs.⁶ However, just what constitutes a fundamental alteration has been the subject of much litigation over the past decade.⁷ Significantly, however, the Court said that States can show that they are reasonably accommodating persons with disabilities if they develop a comprehensive, effectively working plan for placing qualified individuals in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by a State’s efforts to keep its

⁴ *Olmstead*, 527 U.S. at 597.

⁵ *Id.* at 607

⁶ *Id.* at 595

⁷ See e.g.: *Radeszewski v. Maram*, 383 F.3d 599, 613-14 (7th Cir. 2004); *Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175, 1182-83 (10th Cir. 2003); *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003); *Pennsylvania Protection and Advocacy, Inc. v. Pennsylvania Dept of Public Welfare*, 402 F.3d 374 (3d Cir. 2005); *Frederick L. v. Dept of Public Welfare*, 364 F.3d 487 (3d Cir. 2004), and *Sanchez v Johnson*, 2005 WL 1804195.

institutions fully populated.⁸

Data Shows Little National Progress Providing Disability Supports in the Most Integrated Settings Appropriate to the Individual

The data over the past 10 years shows only a modest 11% reduction, nationwide, in the numbers of persons with intellectual disabilities living in public or private institutions (with 7 or more beds). In 1998, the number was 182,490 and in 2006, the number was 159,909.⁹ The data for individuals with mental illness living in state hospitals is similarly disappointing. Twenty years of national state hospital census data (1984-2003) were used to assess trends in the rate of declines from pre- to post-*Olmstead* periods. The data shows a steady decline in census over 20 years, but the decline has slowed significantly during the post-*Olmstead* period.¹⁰

On a state level, the level of progress varies greatly. Some States have made dramatic progress reducing the number of individuals with intellectual disabilities (the data is not available for individuals residing in state hospitals) residing in institutions, while a few states have made no progress.¹¹ As of 2006, the states with the fewest amount of individuals with intellectual disabilities living in their own homes or small group homes (homes with 6 or fewer persons) are: Alabama, Arizona, Georgia, Illinois, Kentucky, Mississippi, South Carolina, Texas, Utah, and Virginia.¹² Another way of measuring progress is to look at the percentages in which States have lowered their spending on institutions. Unfortunately, seven States failed to lower their level of spending on institutions for individuals with intellectual disabilities¹³ in the decade between 1996 and 2006, including: Connecticut, Iowa, Kentucky, Louisiana, Mississippi, Nebraska, and New Jersey.¹⁴

Statistics also show that, nationwide, America continues to spend a greater percentage of its Medicaid long-term-care dollars in institutions rather than on community supports and services. According to a report by Thompson/Reuters, in FY 2007, nationally, only 42% of all Medicaid long term care costs were spent on community-based services, including, home and community-based (HCBS) waivers, the personal care option, and the home health services option. During the same period, 58% of all Medicaid long term care dollars were spent on institutional care, including nursing facilities and intermediate care facilities (ICF) for individuals with intellectual disabilities.¹⁵

⁸ *Olmstead*, 527 U.S. at 605-606.

⁹ State of the States in Developmental Disabilities, at 308.

¹⁰ PSYCHIATRIC SERVICES ♦ ps.psychiatryonline.org ♦ October 2006 Vol. 57 No. 10, p. 1. *State Psychiatric Hospital Census After the 1999 Olmstead Decision: Evidence of Decelerating Deinstitutionalization*, Mark S. Salzer, Ph.D., Katy Kaplan, M.Ed. and Joanne Atay, M.A.

¹¹ Braddock, at 101-305 (state profiles)

¹² *Id.* at 19.

¹³ The author could not find information on level of spending for state hospitals for individuals with mental illness by state.

¹⁴ *Id.* at 9. .

¹⁵ Medicaid Long-Term Care Expenditures in FY 2007, September 26, 2008, By Brian Burwell, Kate Sredl, and Steve Eiken, Healthcare Thomson Reuters, 1 (<http://www.ancor.org/issues/Data-Statistics/Data-Statistics.html>).

The data can be broken out differently to reveal that the shift to community-based care is particularly slow for elderly persons and persons with disabilities other than intellectual disabilities. Specifically, if funding for ICFs is removed, 69% of Medicaid long term care services were spent in state hospitals and nursing facilities and only 31% on community-based services.¹⁶

The slow shift of funding towards community services for the elderly and persons with mental or physical disabilities is in sharp contrast to an AARP survey showing that “89% of people 50 years and older intend to remain in their own homes rather than go to nursing facilities.”¹⁷ The failure to shift dollars to the community also makes no fiscal sense, as demonstrated by a recent AARP study which showed that “[O]n average, Medicaid dollars can support nearly three older people and adults with physical disabilities in Home and Community-Based Services (HCBS) for every person in a nursing home.”¹⁸

So why have some States made significant progress complying with the ADA's integration mandate and others made none? Generally, it is due to a lack of leadership, a lack of responsiveness to the requests or demands of persons with disabilities, and a lack of compliance with federal law. Sometimes, there is opposition to downsizing or closure of an institution among some family members of those in institutions or by unions whose members work in institutions. In addition, legislators representing districts where institutions are situated can be protective of the economic and other benefits they derive from the institutions. The Illinois P&A, known as Equip for Equality, studied this phenomenon in their State and learned

that it is possible to address the concerns of parents of institutional residents, unions, and political representatives without reneging on the state's responsibilities to people with disabilities and their right to live in the least restrictive setting. Common strategies for overcoming opposition to community living included having parents and guardians of family members in the institutions meet with parents whose children have successfully transitioned into the community. Additionally, parents and guardians were sometimes apprised of the many longitudinal studies that show that, despite initial opposition to deinstitutionalization, parents of individuals in institutions had come to view the experiences of their family members in the community as positive, affording a better quality of life than the institution. In the case of unions, their concerns have often been addressed by finding jobs for their members in state-operated community residences or elsewhere in state government.¹⁹

¹⁶ *Id.* at Table I Medicaid expenditures for long-term care services FY 2007.

¹⁷ Across the States Profiles of Long Term Care and Independent Living" (http://assets.aarp.org/rgcenter/il/d19105_2008_atc.pdf), 3

¹⁸ *Id.*

¹⁹ SEGREGATION OR COMMUNITY INTEGRATION: ENSURING THE CIVIL RIGHTS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES IN ILLINOIS (2004) 4 [HTTP://WWW.EQUIPFOREQUALITY.ORG/PUBLICATIONS/CIPPREPORT.PHP](http://www.equipforequality.org/publications/cippreport.php)

The Federal Government Has A Key Role In Ending Unnecessary Institutionalization

In 2001, recognizing the leadership role that federal agencies can have to facilitate *Olmstead* implementation, then President Bush signed Executive Order 13217, which required all federal agencies to evaluate their regulations, policies, and programs to determine whether any should be revised or modified to improve the availability of community-based services for individuals with disabilities.²⁰ The two federal agencies we are reviewing in this report, the U.S. Department of Health and Human Services; and the U.S. Department of Justice completed this evaluation and identified numerous steps they could take to facilitate community integration.²¹

A. U.S. Department of Health and Human Services

The Department of Health and Human Services (HHS) Office of Civil Rights (OCR) is primarily responsible for ensuring that HHS policy promotes access to home and community-based services for individuals with disabilities. As part of that effort, the HHS Centers for Medicare and Medicaid Services (CMS) also has a role to ensure that Medicaid policy is administered in a manner that does not lead to unnecessary institutionalization. Both of these agencies have focused on enforcement but could be much more aggressive and transparent in their efforts.

Office for Civil Rights, U.S. Department of Health and Human Services

OCR is the agency primarily responsible for ensuring that state HHS agencies comply with *Olmstead*. In this role they immediately began educating states about *Olmstead*'s requirements and the possible implications for HHS programs. In particular, OCR advised states concerning development of a comprehensive effectively working plan for moving unnecessarily institutionalized persons into the community.²² On January 14, 2000, OCR and CMS issued a joint letter to state Medicaid Directors indicating that state plan development would be an initial focus of OCR's enforcement efforts. It reads:

Our intent in this enclosure is to identify some of the key principles, including the involvement of people with disabilities throughout the planning and implementation process. These principles also will be used by the Office for Civil Rights as it investigates complaints and conducts compliance reviews involving "most integrated setting" issues. We strongly recommend that States factor in these principles and practices as they develop plans tailored to their needs.

²⁰ See: <http://www.presidency.ucsb.edu/ws/index.php?pid=61498>

²¹ For the DOJ and HHS responses to EO 13217 see <http://www.namisc.org/newsletters/December01/hhs-report.htm>

²² *Olmstead* at 605-606 (The Supreme Court had ruled that such a plan would provide states with a fundamental alteration defense to a judicial finding that the state is in violation of the ADA integration mandate).

This letter also signaled to states that OCR would be investigating complaints and conducting compliance reviews. This program guidance from HHS was a standard against which states and advocates could monitor and assess *Olmstead* compliance. The other component of OCR's enforcement efforts was to encourage disability advocates to file complaints with their office on behalf of individuals who were unnecessarily institutionalized. Unfortunately, neither OCR's intent to hold states accountable to *Olmstead* plans, nor its outreach to citizens to file *Olmstead* complaints, was implemented effectively.

For example, OCR's push for disability advocates to file *Olmstead* complaints, was followed up by an investigation process that frequently excluded the individuals who filed complaints. While not universal, many OCR regional offices failed to acknowledge receipt of complaints or follow-up regarding the outcome of the investigation. The "closed" investigation process also meant that, with a few exceptions, OCR has not consulted with protection and advocacy agencies (P&As) or other advocates when investigating a complaint. P&As could provide OCR investigators with information to help them determine whether the violation is restricted to one resident or is evidence of a systemic failure within the institution.

OCR's non-transparent approach to its investigations persists at the national level as well. The Office has released only raw data and minimal details about investigations and compliance reviews conducted. In the future, we urge OCR to release more information about the process used and specific outcomes of its *Olmstead* complaint investigations. Better data would help states and advocates to assess state compliance efforts, and tell us if OCR is resolving complaints on a systems level. For example, releasing data on the particular settings that are the subject of *Olmstead* complaints, would allow P&As to identify which facilities are frequent settings of *Olmstead* complaints. With this information P&As and advocates would know to reach out to these facilities with training and information on best practices for conducting community needs assessments and discharge planning.

OCR efforts to monitor state *Olmstead* plan development and implementation has also been less aggressive and transparent than what is needed to ensure *Olmstead* compliance. HHS's January 2000 guidelines for state plans seemed promising, but there is no evidence that, after 2002, states plans were reviewed to ascertain compliance with these guidelines.²³

At a minimum, OCR needs to begin, on an annual basis, tracking whether states are making progress reducing their institutional census or decreasing institutional spending. States that are not making noticeable progress ending inappropriate institutionalization should be feeling public pressure from OCR to make changes or face a DOJ lawsuit. OCR could also track which states have applied for the federal grants made available

²³ In 2002 the US DOJ did issue a letter of corrections that cited *Olmstead* and referred to the guidelines for "state *Olmstead* plans" that were set out in the January 2000 letter, See http://www.usdoj.gov/crt/split/documents/laguna_honda_hosp.pdf

over the past decade to incentive state spending on home and community-based services. Those states that did not apply for any of these programs could be prioritized for OCR technical assistance and assessment of *Olmstead* compliance. OCR should also put the U.S. Department of Justice on notice that these states may be violating the *Olmstead* mandate.

Data shows that seven states have failed to decrease their spending on institution services,²⁴ Yet, OCR does not appear to have questioned these states' *Olmstead* compliance efforts. If OCR has done so secretly, it is time to break the silence. Reprimanding a state secretly is not nearly as effective an enforcement tool as if the state is publically warned to increase its compliance efforts.

On a funding level, OCR's ability to enforce *Olmstead* aggressively over the past 10 years has been hamstrung. In the year of *Olmstead's* passage, a Commission report stated that:

OCR operates under severe budgetary constraints . . . OCR's responsibilities and workload have increased over the past several years, yet its funding and staffing have decreased. OCR's budget has fluctuated around \$20 million since 1981, and has not kept up with inflation.²⁵

Three years later the Annual budget for OCR was not significantly increased²⁶ and yet OCR enforcement responsibilities had greatly expanded to include not only oversight of *Olmstead*, but also of the Health Insurance Portability and Accountability Act. Happily, this funding trend is beginning to change. The 2008 -2009 budget contained a six million dollar increase, and the 2009-2010 budget has a slight one million dollar increase. A tight budget however, does not excuse a failure to approach *Olmstead* enforcement more systemically and to reach out to P&As and disability advocates as a component of its enforcement reviews. Neither should it mean so few compliance reviews are conducted, nor effect whether details of these reviews are made known to the public.

Centers for Medicare and Medicaid Services (CMS), Department of Health and Human Services

CMS can provide the regulatory framework for States to rebalance Medicaid long-term care funding to facilitate community integration. Unfortunately, over the past 10 years, CMS has not appeared aggressive in its efforts to look for policy changes that would promote community integration. First let's switch from what CMS could have done to what the U.S. could have done to promote compliance with the *Olmstead* mandate. The U.S. Congress has not been as helpful as it could be to advance movement from institutions to the community. Specifically, Congress has passed mainly short term

²⁴ Braddock at 9.

²⁵ U.S. Commission on Civil Rights - Funding Federal Civil Rights Enforcement: 2000–2003, published April 2002 available at: <http://www.usccr.gov/pubs/crfund02/report.htm>

²⁶ Budget of the United States Government, Fiscal Year 2003, at 466.

financial incentive programs that states can voluntarily apply for in order to receive funding to promote movement from institutions to the community. Some of the major financial incentives Congress has passed over the past decade include:

- Congress in 2000 created the Real Choice Systems Change grant program. Between June 2001 and June 2008, over 8 funding cycles, 342 Real Choice Systems Change grants have been issued awarding approximately \$270 million to the 50 states, the District of Columbia and two U.S. territories²⁷.
- Section 6071 of the 2005 Deficit Reduction Act, created the Money Follows the Person Rebalancing Demonstration, which makes it easier for states to apply for home and community based waivers. The program authorized \$1.7 billion in grants to states and lasts from 2007-2011.
- Another section of the Deficit Reduction Act established a demonstration program so people with disabilities will receive a single comprehensive assessment on the date of discharge from a hospital. The purpose of the "comprehensive assessment" is to "determine the appropriate placement of such patient in a post-acute care site. The "assessment instrument" establishes a presumption for community-services, and a hospital protocol that focuses on home and community-based services.
- the Health Insurance Flexibility and Accountability Initiative, one aspect of which is to make it simpler and easier for states to submit waiver requests and to have those requests promptly considered.

These programs have been vital to some states that have moved individuals out of inappropriate institutions and into the community with supports²⁸. However other states applied and did not receive funding or never even applied for funding. Another big problem with Congressional reliance on short-term grants to re-balance Medicaid is the constant threat that as the *Olmstead* decision becomes a distant memory Congress will shift their funding to newer priorities and *Olmstead* grants will dry up.

It would be much quicker if Congress facilitated *Olmstead* compliance by changing the Medicaid statute. Current Medicaid law makes it mandatory for all states that participate in the Medicaid program to provide institution based care for those who need it. On the

²⁷ <http://www.cms.hhs.gov/RealChoice/>

²⁸ The largest of these grants is the Real Choice Systems Change grants, which include: the Money Follows the Person Initiative; the Independence Plus Initiative; a national state-to-state technical assistance program for community living at Rutgers University; family-to-family health care information and education centers; community-based treatment alternatives for children; respite care for children; and technical assistance for consumer task forces; respite care for adults; and 2 demonstration projects, including, one to assess a new definition of homebound for purposes of Medicaid coverage; and the second, to attract and retain home health workers.

other hand, there is no requirement for states to provide home and community based services for those who need it, provision of these services is optional. This is known as Medicaid's institutional bias and it is a statutory requirement that hinders compliance with the Olmstead mandate. For nearly a decade, some members of Congress have introduced bills attempting to correct the institutional bias in Medicaid law.²⁹ Unfortunately, these bills have not passed.

Switching from what Congress to do, back to what CMS can do to enforce Olmstead, there are many ways CMS can promote *Olmstead* enforcement without needing Congressional action. Over the past decade CMS has done some work in this area, but with national data still showing that more funding goes to institutions than to the community, it is clear more needs to be done. Some examples of CMS *Olmstead* related efforts in the past decade include:

- clarifying that Medicaid waiver funds can be used to cover one-time transition costs associated with moving and to purchase medical equipment for nursing facility residents in the process of transitioning to the community;
- providing guidance on how to use existing CMS Medicaid data (known as minimum data set) to identify individuals who are in nursing facilities and have indicated an interest in moving to the community with supports. The guidance also discussed the reasonable accommodation requirements of Title II of the ADA.
- working with HUD to coordinate Medicaid HCBS transition programs with HUD housing. Collaboration is vital because Medicaid does not pay for room and board. Some examples of CMS coordination with HUD over the past decade, include: the Access Housing initiative which targeted 2000 vouchers over 5 years for persons transitioning out of nursing facilities; awarding funds to housing authorities to improve accessibility in public housing; and removing policy barriers that made it difficult for people with disabilities to utilize housing vouchers.

CMS policy has not always supported community integration, however. For example, on December 4, 2007, CMS issued an interim final rule on case management services.

The rule restricted payment for transitional case management, a vital support for individuals with disabilities. Advocates and providers submitted comments to CMS arguing that the rule would make it more difficult for community providers to offer individuals with mental illness coordinated mental health, substance abuse, and primary care.³⁰ Despite knowledge of its negative impact, CMS went forward with the rule.

²⁹ Examples of allowing individuals eligible for skilled nursing facility care to receive community based attendant services, include: The Medicaid Community Attendant Services and Supports Act (S. 971); the Community Choice Act (CCA) (S683/HR1670) and the Community First Choice Act included in a 2009 Senate health reform proposal.

³⁰ <http://www.ncd.gov/newsroom/publications/2009/pdf/ProgressReport.pdf> at 33.

CMS has also failed to accept advocates recommendations on low-cost, simple ways to remove administrative barriers to community integration. For example: broadening state authority to cover “nurse delegated” services (nursing services that a nurse can legally delegate under state law to a lower level qualified provider – thus reducing the cost and increasing the possibility that an individual can find a community-based provider of the needed service); and prohibiting states from requiring that beneficiaries be homebound before they can receive home health services. This reluctance to remove known regulatory barriers to community integration – perpetuates the feeling that *Olmstead* compliance is not taken as seriously as a civil right.

The good news is that the current Administration was willing to partially rescind the harmful rule on Medicaid coverage of targeted case management, May 6, 2009. Also that summer, the Administration broadened state authority to cover “nurse delegated services” and loosened Medicare’s homebound requirements. Another positive step forward is the recent draft regulations which would eliminate the diagnosis based criteria for Medicaid waivers, and replace it with the more encompassing “needs based” criteria. Hopefully, these long awaited regulatory fixes will continue.

One area ripe for HHS program guidance relates to the connection between Pre-Admission Screening and Resident Review (PASRR) and *Olmstead* enforcement. PASRR is a provision of federal Medicaid law.³¹ It requires states to screen individuals with intellectual disabilities or mental illness prior to placing them in a nursing facility, to determine whether the individual requires nursing facility level services or whether their needs can be met in the community. PASRR is designed to prevent inappropriate placement of people with intellectual disabilities or mental illness in a Medicaid certified nursing facility when community living is appropriate. PASRR also requires states to provide people with these disabilities living in nursing facilities with the therapy and health care that would assist them to be able to move to the community.

In 2006 The HHS, Substance Abuse and Mental Health Services Administration, issued a report on PASRR implementation in nursing facilities and found that 34 states have “some consideration of PASRR within the broader context of their *Olmstead* planning”³². HHS went on to recommend that CMS “Increase guidance to States, clarify/modify certain regulations.”³³

CMS should fulfill this recommendation and issue guidance clarifying that: 1) a PASRR determination that a nursing facility is needed should only be made by a staff member adequately trained in meeting mental illness needs; and 2) If an individual is found to require specialized services to treat their mental illness, the State Medicaid agency ultimately is responsible for providing or arranging for provision of those specialized

31 Nursing Home Reform Act under the Omnibus Reconciliation Act (OBRA) of 1987, as amended by OBRA 1990, 42 USC 1396r (e) (7), later revised by the Balanced Budget Act of 1996.

32 “PASRR Screening for Mental Illness in Nursing Facility Applicants and Residents” at: http://nasmd.aphsa.org/medicaid_mental/docs/PASRR_Screening_for_Mental_Illness_in_Nursing_Facilities.pdf page 35.

33 *Id.* at 37.

services.. The guidance would also encourage states to: 1) have a policy linking people found eligible for “skilled nursing facility level of care” to appropriate community based services to support these needs; 2) request permission from CMS to obtain and use Medicaid data to identify people in nursing facilities who have indicated they wish to leave; and 3) expand PASRR reviews to include individuals with brain and spinal cord injuries.

B. The U.S. Department of Justice (DOJ)

Civil Rights Division, U.S. Department of Justice

The DOJ Civil Rights Division (CRD) has enforcement authority for the ADA Title II, and the “integration mandate” regulation. Yet, a CRD October 2008 report to Congress on DOJ enforcement of the Americans with Disabilities Act “*Access for All: Five Years of Progress Enforcing the ADA*” includes no mention of the *Olmstead* decision or any Division efforts to enforce the integration mandate of Title II. This is not to say that the DOJ has not enforced *Olmstead*, it has done so, but it has never brought a suit primarily to ensure *Olmstead* compliance.

As of the time this research was completed, in September 2008, DOJ *Olmstead* enforcement has been a secondary outcome of DOJ’s main focus which is squarely on enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA). CRIPA allows the DOJ to investigate conditions in public residential facilities and to take appropriate action if they see a pattern or practice of unlawful conditions, such as abuse or neglect that deprives persons confined in the facilities of their constitutional or federal statutory rights. DOJ indicates in its 2008 *Report of Activities to Enforce CRIPA* that one aspect of CRIPA enforcement is to “ensure that public officials operating healthcare facilities are taking adequate steps to provide services to residents in the most integrated setting appropriate to their needs”³⁴

From January 20, 2001 through September 30, 2008, the Division opened 94 CRIPA investigations, issued 71 findings letters, filed 32 cases, and obtained 69 substantial agreements.³⁵ As is the case with U.S. HHS, data available concerning DOJ enforcement of ADA integration mandate is available but is not comprehensive. This National Council on Disability spoke of this problem in a 2005 report stating that:

In short, DOJ’s annual reports make it impossible for Congress or other interested parties to monitor DOJ’s work. More important, the absence of strong annual reports undermines DOJ’s ability to leverage its work through voluntary compliance and serves to discourage people in institutions from reporting illegal conditions in institutions to DOJ. .. [NCD] *Recommendation:* DOJ should improve its CRIPA enforcement reports to Congress by including the full range of data required under the statute.

³⁴ Department of Justice Activities Under the Civil Rights of Institutionalized Persons Act Fiscal Year 2008 http://www.usdoj.gov/crt/split/documents/split_cripa08.pdf , 19).

³⁵ *Id.* at 2

Doing so will increase accountability and enable the public to better understand the Federal Government's enforcement of the rights of people who reside in institutions.³⁶

The data we have shows that over the past 10 years CRIPA activities have not focused on integration mandate compliance with the same commitment as it does whether the state plans to fix up institutions that have failed to keep residents safe from abuse and neglect.

A particular frustration documented by NDRN is the DOJ's willingness to sign settlements affecting individuals living in institutions without ensuring that residents will receive services in the most integrated settings appropriate and a failure to collaborate with the P&A systems when completing CRIPA investigations. These frustrations were also expressed by NCD in 2005 in a report to Congress that recommended:

[CRIPA] Department staff should err on the side of being more, rather than less, prescriptive in case settlements. Department staff should insist on specific outcomes rather than more general policies and procedures to remedy violations and guard against regression when monitoring ends [and] DOJ should make better use of local protection and advocacy agencies charged with investigating abuse and neglect in institutions, and other nonprofit advocacy organizations with well-established records of protecting the rights of people in institutions.”³⁷

DOJ CRIPA settlements can be an important vehicle for ensuring state *Olmstead* compliance. Yet, an NDRN review of several proposed and approved CRIPA settlement agreements reached by the DOJ between 2005 - 2009 with states and municipalities, revealed that the focus of these settlements was heavily tilted toward improving conditions at facilities and little on ensuring residents will be receiving services in the most integrated settings appropriate to their needs.³⁸

In considering the essential provisions for a DOJ CRIPA settlement, minimum requirements for any agreement should include adoption of the principal of providing services in the most integrated setting and the recognition and acceptance that all individuals can be served in the community. A settlement should ensure: individual involvement; informed decision-making and choice; person-centered planning; transition planning; implementation of plans; developing and expanding community capacity; monitoring of community placements; and quality assurance. Until future DOJ settlements focus on community integration, instead of just improving services in already failing institutions, the Department is virtually guaranteeing that institutions remain the *status quo* for individuals with disabilities.

36 The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise??, by the National Council on Disability August 8, 2005 <http://www.ncd.gov/newsroom/publications/2005/personsact.htm#appendixiii>

37 *Id.* at “Executive Summary.”

38 This report and press release, “National Disability Rights Network Applauds “Year of Community Living”, Continues to Question Department of Justice Pouring Millions into Preservation of Failed Institutions,” is available at <http://www.ndrn.org/media/default.htm>

In addition, DOJ should clarify some oft litigated ADA integration mandate questions. One method of clarification is to issue “DOJ findings letters.” Excerpted below is an April 2003 DOJ “letter of findings” regarding an agreement entered with San Francisco in July 2001 under its CRIPA authority. The DOJ and HHS, OCR conducted a joint review of the California Laguna Honda Hospital and Rehabilitation Center (LHH) and issued these findings related to the City’s compliance with Title II of the ADA. It is one of very few good examples of DOJ clarification of *Olmstead* requirements:

[DOJ and OCR] have identified several areas of deficiencies that contribute to the unnecessary isolation of qualified residents at LHH. These areas include inadequate assessments, inadequate discharge planning, and inadequate capacity in the community to meet the needs of LHH residents for whom community placement is appropriate³⁹.

The letter goes on to list specific actions that “at a minimum” LHH and San Francisco must take to remedy including:

Allocate adequate funding for, or otherwise provide home and community-based services to ensure that LHH residents are not unnecessarily isolated at LHH; and 2) Develop and implement a system-wide assessment of various subcontracted community programs to identify network gaps as well as areas of highest demand, and to provide a basis for comprehensive planning, administration, and resource targeting in San Francisco.⁴⁰

Another mechanism for clarifying integration mandate requirements is by filing or intervening in cases that raise questions about the scope of the legal mandate. As the National Council on Disability (NCD) noted in its 2000 report “Promises to Keep: A Decade of Federal Enforcement of The Americans with Disabilities Act”:

The Department of Justice's ability to enforce ADA is not restricted to waiting for individuals with disabilities to file complaints of violations. Compliance monitoring refers to proactive measures to assess and ensure conformance with the requirements of a law in advance of the report of a violation.⁴¹

The NCD report further explains that:

Title II of the ADA ... is subject to the same remedies, procedures, and rights set forth in Section 505 of the Rehabilitation Act of 1973. [which]... is subject to the same remedies, procedures, and rights

³⁹ See, http://www.usdoj.gov/crt/split/documents/laguna_honda_hosp.pdf Page 3.

⁴⁰ *Id.* at 25.

⁴¹ ” at: http://www.ncd.gov/newsroom/publications/2000/promises_2.htm

[See section 2.4 Compliance monitoring]

set forth in title VI of the Civil Rights Act of 1964. Under the Department of Justice's regulations implementing Title VI, the Department shall conduct periodic compliance reviews of recipients to determine whether they are complying with Title VI. (28 C.F.R. § 42.107(a).) Thus, through this chain of references, the Department has authority to conduct compliance reviews under [ADA] Title II.⁴²

The Obama Administration has indicated that it intends to move in this direction. Hopefully, future reports will show examples of DOJ cases brought to enforce the Olmstead mandate; DOJ intervention to support plaintiffs in Olmstead cases brought by private attorneys; strong community integration requirements in all relevant CRIPA settlements; and a focus on the importance of person-centered transition planning; and Olmstead compliance in all relevant CRIPA investigations.

Other methods of DOJ *Olmstead* guidance need to continue. For example, it is vital that DOJ clarify the meaning of the language in *Olmstead* which states that, "Nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings."⁴³ A few courts have held that states must maintain institutions just so that individuals living in an institution can remain in their current institution.⁴⁴ The majority of courts, however, have held that there is nothing in *Olmstead* that suggests that a state has to provide institutionalized care at the facility of the resident's choosing. The integration mandate is simply the right to be transferred to a community placement, if medically appropriate and if the State can reasonably accommodate the placement.⁴⁵

Just as vital is the need for DOJ advice on what constitutes a fundamental alteration in the context of the *Olmstead* decisions. This could include guidance on the interplay between Medicaid waiver cost caps and the integration mandate and re-iteration of the necessary components for a comprehensive effectively working state plan for moving individuals into the most integrated settings.

INDIVIDUALS WAIT NEEDLESSLY IN INAPPROPRIATE SETTINGS

P&As hear from dozens of people each year seeking assistance to avoid or move out of nursing facilities, intermediate care facilities and state hospitals, and return to their own homes, neighborhoods and communities with supports. The stories of just some of these individuals follow.

⁴² *Id.*

⁴³ *Olmstead v L.C. and E.W.* at 601-602.

⁴⁴ These arguments have been presented most powerfully and consistently by the Voice of the Retarded

⁴⁵ See, *Richard C. ex. Rel. Kathy B. v. Houstoun*, 196 F.R.D. 288, 292 (W.D. 1999) *aff. sub. nom*, *Richard C. v. Snider*, 229 F. 3d 1139 (Table) (3d Cir. 2000). By its specific terms, the integration mandate requires movement from more to less restrictive settings, not the reverse. See, *Richard C. v. Houston*, 196 F.R.D. 288, 291-92 (W.D. Pa. 1999).

A 55 year old client with mild intellectual disability and anxiety disorder had been living in a state-operated residential facility since 1969. Because of her anxiety, the client was afraid of the extensive dental work she needed. In 2008, a PADD advocate of the Office of Protection and Advocacy for Persons with Disabilities (the Connecticut P&A) helped the client try an anti-anxiety medication and begin a desensitization process of regular dentist visits. As a result, the client had several successful dental appointments, has made positive strides, and is making a plan for community placement.

A 16 year old girl lived at a state hospital for approximately 8 months due to self-inflicting, harmful behaviors. The client lived in one particular foster home in her home county where she wished to return upon discharge. The hospital agreed she was no longer a suicide risk, but had made no plans for her release. The client's former foster parent called Disability Rights Wisconsin (the Wisconsin P&A) to get her out of the hospital. P&A staff attended discharge planning meetings and helped to prepare an appropriate plan of services. She now lives with the foster family of her choice and is doing well in the community.

Indiana Protection and Advocacy Services (the Indiana P&A) helped a 23-year-old man with quadriplegia from a spinal cord injury who wished to remain in his temporary home, given to him through community placement. The client was happy with the fully-accessible home in which he had a spacious room, roll-in shower, and private deck. However, his insurance company and case manager informed him that the placement was only temporary. The client's provider determined he could stay if he received more hours of personal care assistant (PCA) supports. At the client's request, PAIR staff helped him complete and submit a PCA appeal to the Department of Human Services (DHS), which determined he needed a higher number of PCA hours for proper care. The increased PCA hours enabled the client to remain in his chosen home where he is currently enjoying freedom to date his girlfriend, investigate post-secondary school options, and maintain his health.

A 41 year old female with traumatic brain injury, intellectual disabilities and substance abuse, contacted DisAbility Rights Idaho (the Idaho P&A) while residing at a state facility. The client requested assistance to enter into a community outpatient addiction recovery rehabilitation program she was told was necessary prior to a discharge from the facility. PAIMI staff ensured that her discharge was planned and helped facilitate transportation in the community. As a result of PAIMI intervention, the client completed appropriate programming, was discharged, and is living independently in the community with community supports.

Ohio Legal Rights Service (the Ohio P&A) helped a client who lived in a nursing facility for more than a year and wanted to live in a home or apartment. PAIMI staff attended team meetings and negotiated with staff and the client's guardian to permit discharge to a home of the client's choice. However, the manager denied her application based on presumptions about her ability to succeed in independent housing because of her mental illness. PAIMI staff represented the client at an informal hearing to challenge the denial of her application. The management reversed its decision and accepted the

client's application for residency. PAIMI successfully protected the client from discrimination based on disability, as well as her fair housing rights and right to accommodations.

South Dakota Advocacy Services (the South Dakota P&A) assisted a 67 year old male with severe depression and diabetes. The client's treating physician considered placing him at the state inpatient psychiatric hospital because he feared the client lacked the ability to take care of his medical needs at home. PAIMI staff contacted the state's adult services department regarding funding and home health care service options. PAIMI staff also contacted several of the client's support systems in the community. A civil commitment hearing was scheduled, and PAIMI staff met with the client's court appointed attorney and the qualified mental health professional conducting an evaluation to determine whether to recommend long-term psychiatric care. Because of PAIMI involvement, the petition for commitment was dismissed and the client was discharged with more services and supports in place to continue living independently in the community.

Disability Rights Oregon assisted a 12 year old with autism and bi-polar avoid institutionalization and obtain appropriate community supports. The child's mother called requesting assistance accessing services for son. The school had told her that the child was not welcome to return to any of the schools in the rural district. The district told the mother that in order to get needed services she should sign over her parental rights and make her son a ward of the state. The district said that if client hurts his sister then the state would take both of the son and daughter away from their mother. The client has episodes where he is emotionally distraught, kicks, throws himself, shakes his head, etc and he can sometimes hurt others in the process. These episodes are part of his disabilities. The district refused the mother's requests for an aide. The P&A helped the mother fight institutional placement. Instead appropriate services were found in a day treatment program. The child is receiving services and still able to return home with his family in the evenings.

RECOMMENDATIONS FOR THE OBAMA ADMINISTRATION

In fulfillment of this Administration's commitment to "The Year of Community Living" HHS and DOJ must move beyond use of voluntary incentives, and spur on stubborn states with mandates. States have had 10 years to beef up their community integration infrastructure. For a handful of states the voluntary approach has been effective – populations and funds are shifting. For the other states the time for voluntary action has expired. In these states people are not moving off of community support waiting lists at a reasonable pace; Olmstead plans have not been implemented and institution censuses have barely declined. This is the Year for Community Living – the time in which civil rights are taken seriously. NDRN urges the following recommendations:

A. Department of Justice:

- File and intervene in cases to support full enforcement of the ADA Integration mandate.
- Strengthen the community integration aspects of all future CRIPA settlements.
- Clarify some questions regarding the integration mandate on which federal courts are split

B. Health and Human Services, Office of Civil Rights:

- Prepare an annual report of state institutional census. This would include tracking whether states are making progress reducing their institutional census. States that are not make noticeable progress ending inappropriate institutionalization should be under public pressure from OCR to make changes or face a DOJ lawsuit.
- Work collaboratively with P&As and disability advocates to supplement *Olmstead* compliance reviews.
- Conduct annual reviews in selected states which have failed to implement plans that met the basic components identified in the January 14, 2000 HHS letter to state Medicaid Directors.
- Communicate with DOJ regarding state efforts, or lack thereof, to ensure that individuals receive services in the most integrated settings appropriate to their needs. Issues to report on could include: States which have reduced home and community based programs; States that have not reduced populations in either state hospitals, ICF's, or nursing facility populations; and states that have not applied for Medicaid community integration incentive programs.

C. Health and Human Services, Center for Medicare and Medicaid Services:

- Continue to collaborate with HUD, including announcing an expectation that State Medicaid Agencies will coordinate funding and programs with state housing finance departments, and state community development agencies;
- Issue guidance to clarify PASRR requirements focusing on its role in promoting community integration and preventing unnecessary placement in a

nursing facility. Coordinate with DOJ to facilitate better enforcement of PASRR requirements.

- Issue guidance clarifying that EPSDT can cover teenagers from 18 to 21 and explaining promising practices in transition services.
- Issue guidance offering best practices in short-term mental health crisis services. States that increase their crisis service capacity can minimize costly and disruptive hospitalization.

CONCLUSION

This report has highlighted problematic trends in the federal approach to enforce the *Olmstead* decision over the past decade. It is simply unacceptable, that after ten years there has been little progress in reducing the numbers of Americans with disabilities, nationwide, who live in institutions. The National Disability Rights Network offers this report and recommendations with the hope that federal enforcement of the *Olmstead* mandate by the U.S. Department of Justice and the U.S. Department of Health and Human Services -- the two agencies charged with enforcement -- will turn the promise of the *Olmstead* decision into a reality for all individuals languishing needlessly in institutions.